OLR Bill Analysis

SB 465 (File 107, as amended by Senate "A")*

AN ACT REQUIRING NEWBORN SCREENING FOR ADRENOLEUKODYSTROPHY.

SUMMARY:

This bill requires all health care institutions caring for newborn infants to test them for adrenoleukodystrophy (ALD), unless, as allowed by law, their parents object on religious grounds. Like existing law that requires these institutions to test infants for cystic fibrosis, severe combined immunodeficiency disease, and critical congenital heart disease, the test for ALD is not part of the Department of Public Health's (DPH) newborn screening program for genetic and metabolic disorders. That program, in addition to screening, directs parents of identified infants to counseling and treatment.

Under the bill, health care institutions must begin testing infants for ALD after both of the following occur:

1. a reliable ALD screening method is developed and validated that uses dried blood spots and quality assurance testing methods or (b) the federal Food and Drug Administration approves an ALD test that uses dried blood spots and

2. any reagents necessary for the screening test are available.

*Senate Amendment "A" (1) removes the requirement that health care institutions perform ALD screenings as part of the DPH newborn screening program and (2) adds the conditions that must occur before the ALD screening requirement takes effect.

EFFECTIVE DATE: October 1, 2013

BACKGROUND

Adrenoleukodystrophy (ALD)

ALD is a genetic disorder that causes the accumulation of very-long-chain fatty acids in the nervous system, adrenal gland, and testes, which causes a range of neurological, physical, and behavioral symptoms. While females are genetic carriers for the disease, it primarily affects males.

Generally, the disorder appears between ages four and eight, although milder forms can occur in adulthood. Childhood onset results in a long-term coma approximately two years after the development of neurological symptoms. The child can live in this coma for as long as 10 years until he or she dies.

There is no specific treatment for ALD, but eating a diet low in very-long-chain fatty acids and taking special oils (called Lorenzo's oil) can lower blood levels of these fatty acids.

COMMITTEE ACTION

Public Health Committee

Joint Favorable
Yea 28 Nay 0 (03/11/2013)

Appropriations Committee

Joint Favorable
Yea 48 Nay 0 (04/30/2013)

Finance, Revenue and Bonding Committee

Joint Favorable
Yea 50 Nay 0 (05/14/2013)